



Care for Carers

A short study of the quality of hospital care across Bradford District for carers of people living with dementia

What is Healthwatch?

Healthwatch Bradford and District is an independent organisation which gives people a stronger voice to influence health and social care services.

Good or bad, we want to know what people think of the care they receive in the Bradford area. We record all the views and concerns that we hear from people, and look for patterns which show us how to prioritise our work.

We make sure service providers and commissioners (the people who plan and buy health and social care services) hear these concerns and use this information to shape and improve their services.

Listening to local voices can help create services that really meet the needs of our local communities.

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Introduction

In October 2013 Healthwatch Bradford and District identified a need to undertake a review into the standards of care provided in hospitals across Bradford District for people living with dementia and their carers.

The proposal was initiated by a number of concerns raised by the Adult Safeguarding Team in May 2013 about the varying standards of care; care that could range from excellent to extremely poor. These concerns prompted Healthwatch to undertake an Enter and View visit at Airedale General Hospital Ward 1, Elderly Ward in August 2013. Although the Enter and View visit provided Healthwatch with some understanding of carers' experiences, both good and bad, we wanted to hear more about how carers' experiences can improved.

We aimed to get a better picture of how carers' needs were being met, to understand if the environment was suitable and to help identify solutions that would create a more positive experience. This report provides a snapshot of what we heard from carers and is based on comments and conversations with thirty carers between November 2013 and January 2014.

There are lots of central and local government plans to improve the awareness about dementia and we know NHS Trusts in the Bradford district are actively working towards improving their services. Both Bradford Teaching Hospitals NHS Foundation Trust and Airedale NHS Trust will continue key actions for areas of improvement with a focus on dementia care. Healthwatch has agreed with the Trusts that the findings of this report will help to shape and influence these plans.

The key findings of this short study will come as no surprise to the hospitals and they will be aware of many of the things we highlight. However Healthwatch anticipates that this report will draw attention to the voice and experiences of people who rely on their services, and we hope the voices of carers are listened to when decisions are being made about shaping and improving dementia care at the hospitals.

Healthwatch knows there is much more listening to do and there are many more carers of people with dementia across the district who have not shared their experiences. Both hospitals have agreed to respond to this short report and Healthwatch will then re-visit the experiences, voices and views of carers of people living with dementia, once actions have been implemented.

Healthwatch Bradford and District

April 2014

How we gathered views

Healthwatch understands the pressures carers experience and wanted to make contributing to this review as easy and accessible as possible. We designed a simple questionnaire which asked four questions focusing on environment and the quality of care for both the carer and someone living with dementia. The final question explored gaps in services and what needed to be put in place to help support carers more effectively. The questionnaire was also made available online.

Healthwatch worked with voluntary, community and statutory sector partners to help identify carers of people with dementia and encourage them to share their experiences. These included the Alzheimer's Society, Carers Resource, Holme View Care Home Carers Group and Age UK Bradford and District.

We also asked people who are in touch with Healthwatch to talk to people in their communities, to be the eyes and ears of Healthwatch and gather the experiences of carers of people living with Dementia.

Healthwatch wanted to make it easy for people to contribute to the review so we went out to talk to carers at five different locations across Bradford, working with a community organisation called The Memory Club which offers social support to both carers and people living with dementia from across the district. The groups meet every two weeks in Keighley, Saltaire, Shipley and Idle. We also spoke to carers attending the Wellbeing Cafe at Grange Interlink Community Centre, which supports carers from a South Asian background.

In total we heard from thirty carers from across the District, twelve by questionnaire, four completed the online survey and fourteen carers told us about their experiences during our conversations with them.

These conversations helped Healthwatch to gain a better understanding of the hospital care people received. Many of the comments were positive and it became clear that people's recent experiences of services was better than peoples experience of services up to two years ago.

What we heard

A range of key themes emerged during our conversations and it became clear where things worked well, where things didn't work so well and where things needed to be improved. Healthwatch identified key themes from what we heard which included:

- **Listening to carers and involving them in care**
- **The Quality of Care**
- **The Care Environment**

Listening to carers and involving them in care

Some of the people we spoke to were positive about the communication and support that they had received as a carer. However others gave accounts of poor communication and gave examples of how failing to involve the carer in planning and providing care had caused difficulties. Mrs A's story illustrates the point.

A carer's view: Mrs. A

Airedale General Hospital, Ward 1, 2013

Mrs A has been caring for her husband who has been living with dementia for approximately eight years. Three years ago Mr A's condition led him to take residence in a local care home. Mrs A is 78 years of age and has a number of health problems including arthritis and back and knee problems. However she still has a very active and important role in his care.

Mr A was taken into hospital last year (2013) and was placed on the elderly medical ward (Ward 1) for three days. Mrs A talked to Healthwatch about this experience:

"When I wanted to know what was wrong with my husband and asked the nurse what the problem was, she said she would get the notes and let me know but did not come back.

"One day he had wet his bed and the nurses were going to change the bedding. I was asked to go to the day room and wait while they did this. They tried to change the bedding but because they found his behaviour challenging they left him with the wet bed. I was told I could come back to the bedside but not informed that they had been unsuccessful in changing the bedding. It was only when he became agitated and began to kick the bedding about I noticed the wet patch again."

"When I approached the nurse to ask them to change the bedding the response I received was 'he wouldn't let us do it and was aggressive, we only have two nurses and two healthcare staff for fifteen patients'.

"My husband became agitated and distressed, kicking the bedding, about. I just felt sorry for my husband and very helpless. I wonder what would have happened if I was not there. You see, at the care home they have care staff that understand the behaviour and would have gone back to him, but at the hospital he was just left. It's upsetting and disrespectful, where is the dignity in care?

"Why didn't they tell me they hadn't managed to change the bedding? And why did they not ask me to help? Staff don't know how to handle the situation, they need more training and information on dementia.

"They need more people who understand dementia and they need more dementia nurses. The biggest problem is nurses don't understand dementia.

"The good thing about it was I was able to visit him when I wanted to and able to stay longer if needed to. I have to say A&E has been fabulous, no complaints. We have been four or five time and we have had no problems, seen quickly and the doctors and nurses were aware of his dementia. Problems start once you are on the ward because they don't have the knowledge."

This carer's experience raised concerns about communication among staff as well as with the carers, the importance of identifying and involving the carer during the care sequence and in particular the importance of listening to the carer. We found this theme was strongly linked to limited knowledge of dementia among staff as well as staffing levels. The case illustrates how a lack of good communication leads to inconsistency in care and support received, we found this was the experience of most carers we heard from in addition to this carers told us of the different levels of care and support they get on the same ward.

One carer told us she felt:

“Low staff numbers and the pressures for caring for such large numbers of unwell people means they have to prioritise and carers just aren't a priority.”
Airedale General Hospital

A Carer's View: Mrs. B

Bradford Royal Infirmary, Outpatient appointment, Urology Ward, December 2013

Mrs B is 80 years of age with some health problems and has been caring for her husband since 2012. When Mr B was identified as living with dementia, the GP made a referral to Eccleshill hospital where an assessment was carried out. Mrs B had the opportunity to speak to Alzheimer's Society staff who were present to provide information on dementia and what could be expected, as well as offering support to the carer. She was informed of local support groups such as the memory club and referred to the Eccleshill wellbeing cafe. She spoke to Healthwatch about her experience:

“My husband had an appointment for a bowel scan, I was with him. The nurses took him in before his scan so that he could get changed into the gown. They asked him to get ready and put on the hospital gown. It was a while before I wondered where he was and so I went into the room to look for him.

“The nurses had just left him with the gown; he was left confused and did not know how to dress himself. I went in and helped him get ready.

“They didn't even tell me they were taking him in to get changed; I would have told them he needed help. The nurses just don't understand dementia. They need more training.”

A Carer's View: Mrs. B

Outpatient appointment, Urology Ward, January 2014

Mrs B also told us about her next visit to the department a few weeks later.

“When we arrived we went to the desk and reported to reception and the nurse came and took us to the bay where we would be seen. She took my husband’s details and completed the relevant paper work, as well as checking essentials such as blood pressure etc. They spoke to my husband and also involved me when he was unable to answer the questions, or if the information was incorrect. My husband was unable to have any food or drink before his procedure but they brought me a cup of tea.

“The surgeon came up to explain the procedure; we were both kept informed and given enough information. You hear so many bad stories, so I was worried and didn’t know what to expect, but the staff were considerate of my husband’s dementia, and told us we would be the first ones down and we were. I can’t fault them they were great, and I’ve never seen so many staff.

“It did say on the doors that carers and family could not stay, but I was not asked to leave and had the opportunity to stay with my husband. When he came back after the procedure he was provided with a drink and a sandwich, he was well looked after.

“At the point of discharge we were given all the information we needed, it was a smooth process, just like a conveyer belt. My husband was fine during the whole process which made things easier. I can’t fault the process. It just took away all my worries and made caring easier.”

Like in the cases of Mrs A and Mrs B, most carers felt the communication, support and involvement they received was unstructured.

Another carer, Mrs C, told us of her recent experiences at Airedale General Hospital, Ward 15 in December 2013:

“My husband had an appointment at Airedale General Hospital. When we got there we booked in, they got both of us a wheelchair, it’s a long walk down the corridor so I had a wheelchair too, that was good of them but after that I was just sat in the wheelchair and felt ignored by the doctors who spoke to him the whole time, I was better off staying at home.”

Mrs C acknowledged she was provided with support to meet her mobility needs to join her husband during his appointment however felt strongly about the lack of communication and involvement as a carer, she felt her knowledge and understanding as a carer was not taken into account.

Listening to Carers

Many carers told us they felt they were the experts on the patient's care yet were not involved enough or listened to by staff.

“Doctors, nurses whoever, need to listen to us the carer, we are the experts, we know what they can do or can't do, we care for them, and someone with dementia won't give you the right answer so why ask them the questions?”

“They need to start listening to the carer and stop asking the person with dementia for answers; it's frustrating when the doctors don't let you answer the questions and I know what he is telling them is completely wrong, he is confused.”

Whilst Healthwatch would certainly not suggest that the person with dementia is excluded from conversations and consultations, it is clear from many carers that it would be helpful to involve them too. It is also important to understand that the different stages of dementia will require a different level of communication.

“A few months ago he could put on his own shoes, now I have to dress him and cut up his food, it's changing all the time.”

“They had difficulty getting my Dad to understand them but they didn't contact us for support.”

Language Barriers

Some carers felt it was important to have interpretation services available to improve communication between staff, carers and the person living with dementia. A carer from a Ukrainian background told us about problems staff faced in supporting his father due to language barriers:

“My father kept telling us he was hungry and thirsty. When we asked the staff if dad had eaten, they were unable to tell us if he had eaten or not. I spoke to a doctor and asked them why they had not telephoned me or my sisters or interpreting services if they had problems making my Dad understand them.”

Airedale General Hospital, 2013

It is important to note that some older people may not wish for their carer to be used to translate as it affords no privacy, so it is vital to look at each individual case on its own merit and check what both the person living with dementia and the carer need in order to meet communication needs.

“They were insistent on a neutral translator, and it is likely that my Dad would feel much better if it was the family telling him the information”

Bradford Royal Infirmary, 2012

One carer told us about a more recent experience and found the staff and the interpretation support helpful.

“I support my brother who has dementia; both of us speak little English. The hospital was very good and provided an interpreter to speak to both my brother and me in Urdu, to help us understand and explain the process.”

Bradford Royal Infirmary, Ophthalmology Department, Dec 2013

Providing Information to Carers

Carers felt that they were not always given the right information to help them get support or understand how best to help someone with dementia.

“We would have liked more information to understand how we could better support our Dad. They had bad communication and did not keep us up to date and seemed cagey about giving us information.”

Bradford Royal Infirmary, Coronary ward, 18 months ago

“No one told me anything, they give you a leaflet telling you what it is but don’t tell you what might come next, no one told me I would have sleepless nights because he would wander off or wet the bed.”

Bradford Royal Infirmary

“They should tell people where they can get help, I read about well-being cafes and memory clubs in the Keighley News, and I thought I’d give them a go.”

Sticker Schemes

Both Airedale General Hospital and Bradford Royal Infirmary have sticker schemes that easily help to identify patients living with dementia; the sticker is used on case notes and is placed above the patient’s bed during hospital stays.

There were some concerns about the Butterfly Scheme at Airedale General Hospital, about the use and awareness of the scheme among hospital staff:

“Not impressed with the sign above the bed or on the notes as it’s always at the bottom of the pile and not given any attention.”

“If you are on the Butterfly Scheme, they give them a red tray for meal times, but it’s no use, they still put it at the end of the bed, where he can’t reach it.”

Similarly a small number of carers we spoke to who have had experience within the last six months at Bradford Royal Infirmary made reference to the Forget Me Not Scheme and also mentioned the flower symbol associated with the scheme.

However, a substantial number of carers we spoke to had no knowledge of either scheme, its purpose or how to access the scheme. Others thought they had heard of the scheme but again were unsure what it involved and its function.

“Yes I have heard of that but not quite sure what it is about.”

“I would like to know at what stage they promote these schemes, I mean, when is someone told about it, if it’s not in your notes and you are at the hospital, surely someone should be telling you about it?”

“I didn’t even know about those butterflies, I found out from a friend, I’ve no confidence in them.”

When Mrs B enquired about the scheme on her visit to Ward 15, Airedale General Hospital the staff were unable to provide her with details of the scheme.

“I asked the doctor about the Butterfly Scheme, I said ‘where is his butterfly?’ And he replied ‘I don’t know anything about a butterfly’.”

Quality of Care

Staff levels and knowledge

Some carers had a positive experience when their partner or parent was both inpatients and outpatients. They told us about the “excellent” levels of care at both Trusts, from the environment, promotion of food and drink, to the support received from staff with good knowledge of dementia.

However others were not so positive. Most of the carers we spoke to said that support for carers appeared limited due to the lack of awareness of dementia and its varying nature, and the lack of sufficient staff to cope with the variable demand which placed pressures on staff.

Bradford Royal Infirmary:

“No support! I felt responsible for ensuring my relative was properly cared for and felt guilty when care was not given. The staff genuinely seemed to be rushed off their feet.”

“The care levels were disgusting; they didn’t seem to have time for anything and were not aware of dementia.”

“They just don’t understand how to care for someone with dementia”.

Airedale General Hospital:

“There is a need for more trained nurses in dementia.”

“Staff appeared to be nonexistent at times.”

“Two nurses to 15 patients; they are rushed off their feet.”

Promotion of food and drink

There was a strong concern staffing levels and not involving carers resulted in the lack of promotion of food and drink to patients living with dementia, and a general consensus among the carers that this affected them by causing worry and anxiety. It created a lack of trust in the level of hospital care received, which placed added pressures on the carer who felt responsible for ensuring the person with dementia was receiving the attention and care needed.

Bradford Royal Infirmary:

“My main issues were with the promotion of eating and drinking... relative was frequently left without assistance and had difficulty managing on her own...the staff genuinely seemed to be rushed off their feet.”

“He was often left for long periods of time without food and drink and if I and my family didn’t visit daily these things would have been missed.”

“The staff genuinely seemed to be rushed off their feet.”

Airedale General Hospital:

“Promoting eating, on one ward my father looked like a tramp, his dinner was all down his clothes. My sisters were heartbroken; he had forgotten how to feed himself. When we asked the nurse and told her we wanted a chat, she said “2 minutes” and never came back.”

A Carer's View: Mrs. D

Airedale General Hospital, Ward 1, 2012

“My Husband was admitted into AGH approximately 18 months ago after fainting at home. He was taken in for observation. When he was admitted he was given no water for four hours despite asking for it for it on four occasions and being told "I'm bringing it". I did remind them again when I left.

“That evening he was found in the car park, confused. I got a call at around 9pm from the staff saying that they were struggling to get him in. I am sure he was more confused from not having any water.

“I also did not get a drink until I got really cross and then they bought me a tea and cup of soup. We had had nothing since 8am and we left at 4pm. They brought my husband two small ham sandwiches but still no water.

“When we got to AGH the next day for visiting he was still in his gown with no underpants or a pad on. I had to dress him. He had an old blanket wrapped round his shoulders. He had a butterfly on his locker but it was never even taken notice of by the staff. The old man of bed 92 opposite was treated with the same indignity, he was also just in his gown, out of his bed with his back facing us doing his exercises and I can tell you that was not a pretty sight. I didn't know where to hold my eyes.

“He was discharged that day but was distressed and his dementia was worse. Privacy and care were disgusting - they just didn't seem to have the time for anything and were not aware of dementia. This does not need to be nursing staff but other care help should be available.

“There needs to be greater understanding of dementia and a quiet place where carers can stay longer not just during visiting times.”

A Carer's View: Mrs. E

Bradford Royal Infirmary, Elderly ward, September 2013

“My Dad who has dementia was on a ward specifically for the elderly (including dementia patients) last September 2013. Having queried with staff about Dad's care, we were told that there were no dementia trained staff on the ward! Consequently the staff weren't able to deal with Dad properly. Not their fault - but not helpful to us either.

“The ward was very clean and tidy. The cleaner was very cheerful and friendly even though dad wasn't aware of this. He was given his meals in his room (he was in isolation), and mostly left to his own devices, until we pointed out again and again that he couldn't feed himself or even drink on his own. Eventually the only way we could be sure that Dad was being cared for properly was to be on the ward from 7 am until 8pm. Dad isn't able to communicate, but the staff seemed to think he was being awkward or rude, not their fault if they're not aware of dementia.

“Could I also mention that Dad has been to A & E at BRI several times since then, and has been treated very well, considering the amount of people there at the same time waiting for treatment. Although we came up against the same problem of staff not understanding dementia, and not knowing how to deal with people suffering from it. (Not their fault).

“Bradford Royal Infirmary staff were mostly very nice, caring people, but the ward was understaffed and the staff on duty weren't trained properly. To be able to help someone with dementia, you need to have a basic understanding of the problems caused by it, not necessarily of the illness itself. e.g. : it was no good giving dad a buzzer to press if he needed help - he doesn't understand the buzzer and he can't ask for help !

“Finding that Dad's cup of coffee is still full and cold doesn't mean he doesn't want it - it means he doesn't know what to do with it. At mealtimes if he hasn't eaten, it doesn't mean he's not hungry - it's just that he's not able to feed himself or able to ask for help.

“Just because Dad has an en-suite bathroom, it doesn't mean there is no need to help him with toileting- Dad is doubly incontinent, he would sit all day and not be able to use a bathroom by himself.

“Most of the staff were as helpful as their time and understanding of dementia dictated. Some went over and above their limits to help. Generally support and care were as limited as the staffs' knowledge of dementia.

“Support for carers in general wasn't too good. We got the feeling that we were thought of as overprotective or too demanding. In reality, Dad came home covered in bedsores and wheelchair bound, he hasn't walked since. The nurses were very busy but did ask if we were all right, don't know what the outcome would have been if we had said no, because they had to ask in passing, on their way to another patient.

“I would like to see all staff trained in dementia (just a basic understanding - to see it from the carers/patients point of view). Each ward and A & E unit should have at least one qualified dementia trained staff on duty over 24 hours. Carers should be allocated a member of staff who can be contacted at all times, who has read and understood the patient's notes referring to the type of dementia and problems caused by it. Isolation rooms should have extra large glass windows in view of the nursing station, whereby patients can be monitored at all times, watching for distress or fear.”

Carers shared their thoughts on the hospital environment including places for interaction and signage. From our conversations and questionnaires we had little response from carers about the physical environment, and it became clear that carers had low expectations relating to the nature of the buildings from which services were delivered.

Carers told us the importance of being comfortable within the environment, feeling supported, having the right information at the right time and being involved in the care of the person with dementia.

Carers from different cultural backgrounds told us they felt the surroundings would benefit from being more culturally attuned to support people with memory problems:

“It would promote greater cultural awareness, in terms of comfort in the environment, and familiarity would help my dad especially with his dementia; not sure if they already have this on the dementia ward, we’ve not had to go.”

Bradford Royal Infirmary

Carers were also concerned about the lack of information about and access to elderly care wards and services at the hospital and most were unaware of the both Bradford Royal Infirmary and Airedale General Hospital:

“I didn’t even know about the ward for dementia, if you go in with a heart condition you stay on the coronary ward.”

Bradford Royal Infirmary

Many of the carers we spoke to share the same view:

“It’s no good having all the fancy stuff on one ward, on which there is never enough beds, so you end up on a ward that’s not fit for someone with dementia.”

“What do they think the benefit of a red toilet seat is? It doesn’t mean anything to somebody with dementia; they want to get more people trained up to understand dementia so there is a better level of care.”

The observations made by the carers highlight a need to get better at involving carers with developments made and share the rationale relating to changes to the physical environment. It also illustrates again the need for an increased awareness and training across the Trusts in dementia.

Questions

Listening to carers

- What further steps will the Trust take to involve carers with the indirect and direct care of the person living with dementia?
- How does the Trust check that the carer is seen as the “expert in care” and involved in assessments, planning and delivery of care, in line with their preferences and wishes?
- How is feedback from carers gathered and acted upon?

Language barriers

- How does the Trust plan to overcome language barriers that delay communication between patient and staff? And to what extent will these plans involve carers and family?

Providing information to carers

- What steps does the Trust take to ensure that people with dementia and carers get excellent information to meet their needs and support the carer in their ongoing role?
- What joint working has the Trust put in place with Voluntary Community Sector partners to provide advice, information, signposting or access to other relevant statutory or voluntary sector services?

Sticker schemes

- What further steps will the trust take to make the sticker schemes known and more visible to staff and carers across disciplines?
- Has the Trust evaluated the effectiveness of the Butterfly and Forget me not schemes and tested out the impact on the care and support of people with dementia and their carers? What improvements have been made?

Staff levels and staff knowledge

- What further plans do the Trusts have to increase understanding of dementia amongst all relevant staff and how do these plans involve carers to improve staff knowledge and awareness of dementia?
- Has the impact of this training on the quality of care been evaluated?
- Dementia awareness appears to be an issue for some staff on some occasions, and we would like to know how this issue is to be addressed? How many are trained? How is knowledge shared across disciplines?

- Given the changing levels of need for support for individuals on a busy ward, how does the Trust ensure that levels of staff trained in dementia care are sufficient at any one time, including on occasions the need for one to one support of people with dementia?
- Could steps be taken to give greater priority to people with dementia in A&E? Some hospitals take account of dementia in the triage process.

Promotion of food and drink

- It is clear from the carers we spoke to that issues of nutrition and hydration remain a real concern. What additional steps will the Trust take to ensure that each person with dementia is appropriately supported to eat and drink?

The care environment

- Within the physical constraints of the building stock what steps has the Trust taken to build dementia friendly features into the care environment? What more can be done?

Healthwatch will continue to work with both Airedale NHS Foundation Trust and Bradford Teaching Hospitals NHS Trust to follow up on their answers to these questions and consider what actions they can take to improve the experiences of carers of people with dementia.

Healthwatch Bradford and District plans to re-visit the experiences, voices and views of carers of people living with dementia in the future, once actions have been implemented, to see the impact of any changes.

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